

From: California Foundation for Independent Living Centers (CFILC)

August 5, 2008

Honorable Patty Berg
State Capitol, Room 4146
Sacramento, CA 95814

**Re: Assembly Bill 2747---End-of-Life Options
CFILC Position: Oppose**

Dear Assembly Member Berg:

I am writing to alert you that the California Foundation for Independent Living Centers (CFILC) has reviewed the amendments that were passed by the Senate Health and Judiciary Committees, respectfully, as well as several of the amendments that were most recently offered by CFILC and other opponents to the bill. I regret to inform you, for the reasons described in this letter, that our member organizations have decided that we must continue to maintain our OPPOSED position.

As you may be aware, CFILC is a nonprofit advocacy organization that supports legislation to improve the lives of Californians with disabilities. We are a membership of 27 Independent Living Centers located throughout California that provide a wide range of programs and services that enable over 350,000 people with disabilities to live independently.

CFILC member organizations originally voted to take an oppose position on AB 2747 based on the unique perspectives and concerns experienced by our community, which include direct experience relating to the unreliability of medical diagnoses and prognoses of terminal illnesses. Indeed, many people with disabilities diagnosed with terminal illnesses have survived and thrived for many years beyond predictions of imminent death.

We sincerely appreciated the willingness of your staff and the bill sponsor to engage in good faith negotiations. The amendments made by the Senate addressed many of the major issues underlying our opposition to the bill, particularly with

respect to efforts to offer palliative sedation and voluntary stopping of eating and drinking as end-of-life options. We also welcomed the opportunity to continue working with you and the Senate Judiciary Committee staff to explore additional proposed amendments that we hoped could have persuaded our membership to remove our opposition.

While we were pleased that you and the bill's sponsor agreed to accept additional amendments, we regret that in the final analysis we were unable to reach agreement on three critical issues. The lack of a consensus agreement on these amendments ultimately convinced our membership, as matters of public policy and moral conscience, that we could not remove our opposition and go neutral on the bill.

The first issue is related to the bill's continued use of what we believe is an overly broad and undefined term "end-of-life care" with respect to the information and counseling that health care providers are required to provide to patients diagnosed with a terminal illness. CFILC offered amendments that would have substituted that language with the term "Advanced Directives, Hospice, and Palliative Care," which encompasses the specific types of medical care that is available under existing law to patients with terminal illnesses.

CFILC strongly believes that the lack of specificity as to the exact types of information and counseling to be provided to patients would lead to unintended consequences. Without that qualifying language, we believe that there is considerable room for the bill to be misinterpreted as sanctioning the delivery of information and counseling about forms of euthanasia.

The rejection of these amendments raised serious doubts among our membership about the true intentions of the legislation given the broad and ambitious sweep of the bill that was passed by the Assembly. Our members are aware of the fact that bill's sponsor has a clear, publicly stated mission to promote assisted suicide as a legal end-of-life option and appears to be poised to take a leading role in providing the information and counseling about end-of-life options authorized by AB 2747.

Our concerns in this regard were further buttressed by other provisions of AB 2747 that allow health care providers to use

factsheets and Internet Web site information obtained from **“organizations specializing in end-of-life care”** and that authorize patient referrals to **“community-based organizations that specialize in end-of-life care case management”** (Sec. 442.5, H & S Code). When these provisions are considered in combination with one another, our members have reason to believe that there are insufficient assurances that decidedly pro-assisted suicide organizations could use the bill as a vehicle to provide information and counseling far beyond the scope of advanced directives, hospice, and palliative care.

Moreover, because there are relatively few organizations that have the resources to provide more balanced end-of-life information and counseling, pro-assisted suicide organizations could easily occupy the field in providing end-of-life information to health care providers and operate as a primary resource for referrals. Simply put, we believe that here are insufficient procedural safeguards set into place by AB 2747 that would protect people with disabilities and their families from being unduly influenced or potentially coerced to choose a form of euthanasia.

Our goal in offering our amendments was to narrowly tailor the types of information and counseling contemplated by AB 2747 in order to ensure that it would be sufficiently objective and balanced. At a minimum, patients should be made aware of the imprecise nature of medical diagnoses of terminal illnesses, as well as receiving information and counseling about existing assistive technology, rehabilitation, counseling, and independent living programs that are available for people with disabilities. In addition, patients should be actively encouraged to consult with organizations familiar with helping patients cope with living with specific diseases resulting in a diagnosis of a terminal illness.

While the disability community is familiar with, and confident about, the impartiality of organizations providing hospice care, there is no corresponding degree of confidence about how pro-assisted suicide organizations would approach end-of-life option counseling. Unlike a pro-assisted suicide organization, hospice care organizations have the necessary expertise to impartially evaluate the medical condition of patients diagnosed with a terminal illness and are fully capable of providing

information about the benefits of hospice care, advance directives, and palliative care. Unfortunately, AB 2747 does not include sufficient safeguards to ensure that information and counseling about forms of euthanasia will not be prominently featured as the most suitable end-of-life option.

The lack of any meaningful procedural safeguards or carefully balanced information and counseling is a fundamental concern to the disability community. Historically, people with disabilities have been society's most likely candidates to be influenced or coerced to end their lives because of the common public perception that it is better to die than to live with a disability. Both the U.S. Commission on Civil Rights and the National Council on Disabilities have reported that people with disabilities have been victimized by rampant discrimination, misdiagnosed with terminal illnesses, denied medical treatment, and targeted for involuntary euthanasia.

Given this shameful legacy, we believe that clearly defined and stringent procedural safeguards are essential to protect against the enactment of any statute that would dilute a person with a disability's full control over their medical condition and treatment. Thus, we must oppose any legislation that could lead the way to legally sanctioning assisted suicide or that may intentionally or unintentionally influence or coerce the surrender of their personal autonomy.

Finally, we oppose the provisions of AB 2747 that allow health care providers who do not wish to comply with his or her patient's request for information on end-of-life options to refer or transfer the patient to another health care provider or to provide the information on procedures to make such a transfer (Sec. 442.7, H & S Code). People with disabilities who are diagnosed as having a terminal condition already face significant challenges in obtaining treatment from health care providers, so we are concerned that a simple request by the patient would legitimize the dumping of patients or a transfer to another health care provider simply because the health care provider does not wish to treat them.

Accordingly, for the reasons outlined in this letter, we respectfully submit that we are unable to remove our opposition to AB 2747.

Sincerely,

A handwritten signature in blue ink, appearing to be 'Teresa Favuzzi', with a large loop and a long horizontal stroke extending to the right.

Teresa Favuzzi, MSW
Executive Director

cc: Members of the Senate

Charlotte Maxwell Newhart, CFILC Lobbyist